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Independent living: new goal for disabled persons

By Irving R. Dickman



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Independent living: new goal for disabled persons

By Irving R. Dickman

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MIKE AND EARL are middle-aged bachelors who have shared an apartment in a New York City housing project for five years. Some of their neighbors—even those who know them rather well—consider them an “odd couple.”

They are permanently confined to wheelchairs. Both are quadriplegics as a result of muscular dystrophy, with virtually no use of their arms or legs. That makes them “different”; what makes them “odd” is that despite their handicaps, Mike and Earl are determined never to return to institutional living, but to go on—so long as they do not need active medical treatment—living independently, in their own apartment.

Their determination shows in other ways as well. Earl is taking evening courses in economics at a local college, even though he needs special devices to turn the pages of the books he studies. Mike “has no head for studies,” but is an activist: he’s been a member of his building’s tenants’ committee; during the 1974 gasoline shortage he joined a delegation of disabled people who took their plea for special consideration to city hall—and he has a newspaper photo to prove it. Yet, when Mike sits sunning himself in front of the building, one of his more motherly neighbors is almost certain to ask: “Should you be out here all by yourself?”

John, who has multiple sclerosis, shared an apartment with his mother until she died. As it does with so many of its victims, multiple sclerosis attacked John when he was in his thirties. Determination is also what has made John decide to stick it out in the apartment for as long as physically possible—even though his condition is worsening. He lives alone, confined to his wheelchair—but on his own.

Sheila and Marie needed determination too, because the landlord was “a little nervous” when he was asked to rent them an apartment in Philadelphia. Perhaps understandably: after all, not only are both women moderately retarded but between them they had lived more than 40 years in institutions before they became roommates. Theirs is one of six apartments rented to retarded people in a 90-unit complex. Since mental retardation is an invisible handicap, most of their neighbors are not aware of the “different” tenants among them.

Diane, a paraplegic, and Judy, a quadriplegic, both working in Washington, had a different kind of landlord problem. They found one who was willing to rent to two people in wheelchairs but unwilling to make the few necessary adaptations—until the two women contacted a lawyer and reminded the landlord that District of Columbia laws, like those in many states, provide for “reasonable accommodations” for the disabled.

Both in wheelchairs as a result of cerebral palsy, Vic and Martha met at a social group and eventually decided to get married. But first they had to overcome the reluctance of both sets of parents to see their “children” strike out on their own.

One thread ties all these experiences together. The common reality for nearly all of the small, but growing, number of physically and mentally handicapped people now living independently in communities throughout the United States is not only their extraordinary determination but the opposition they had to overcome. Opposition to their moving out—from their families and the professional people closest to them; opposition to their moving in—from reluctant and even hostile landlords and neighbors.

Not all handicapped people, perhaps not even the majority, can or will ever want to live independently. But a growing number of severely disabled young adults and teenagers are hoping, asking,

planning to live not in institutions, not in the homes of their parents, but like other young people—in homes of their own. And new methods of government funding, new concepts of supportive or standby services by community and voluntary agencies, and new social attitudes, which accept the right of each individual to choose his own lifestyle, are stimulating increasing numbers of disabled people to ask: Why not me, too? More and more disabled people are now able to offer the same cogent argument Vic and Martha did. What triggered their marriage, and their move, they say quite frankly, was the success of Mike and Earl, the two quadriplegics. “If *they* could make it out into the world,” says Martha, “why couldn’t we?”

the right to choose

Recent Bureau of the Census figures estimate that 11 million Americans between 16 and 64 are disabled—suffering from spinal cord injuries, cerebral palsy, multiple sclerosis, muscular dystrophy, mental retardation, blindness, and other handicaps. See-



ing themselves as "outsiders," they—and the organizations serving them—insist they be given an opportunity to join the "mainstream of society."

In recent years this has encompassed what would once have been a revolutionary concept: to give to the handicapped person the opportunity to choose among alternative ways of living. "We support any reasonable and practical efforts to establish living arrangements that will stimulate and satisfy each handicapped person's fullest potential," says a United Cerebral Palsy Associations policy statement. In an American Foundation for the Blind publication there is a call for "a breakdown of the barriers that separate blind people from their neighbors [so they can] abandon their separate world and rejoin the larger community." "The mentally retarded person is entitled to the same civil rights as any other citizen," notes the National Association for Retarded Citizens, citing explicitly "the right to choose a place to live."

What "the right to choose" implies is something even more far-reaching: the right of disabled people to make their own decisions. Many feel this deeply: "I'm tired of able-bodied people sitting behind desks in ivory towers making decisions about my life," one woman remarked bitterly. "Only if you sit in a wheelchair can you tell how people in wheelchairs feel."

One of the strongest statements in support of this right was made in 1974 by Gerald R. Ford, who was then Vice President, before the President's Committee on Employment of the Handicapped: "Handicapped persons are very correctly demanding a piece of the action. You want to take part in the decision-making processes that affect your lives. You want a voice and a choice. You are asking for your God-given rights and your inalienable liberties as American citizens. . . . I invite your involvement in your own destiny. . . ."

It is true that in recent years some handicapped people have been able to break through the barriers that kept them from the mainstream. But the breakthroughs have been sporadic and the people exceptional: the deaf boy who made it from the special school for the deaf to an ordinary high school was always on the dean's list; the quadriplegic who won his battle to practice law in New York without having to take the bar exam—because

of the discomfort of sitting so long—had a 3.5 average in four years of law school.

However, it is still, as Harold Russell, himself a double amputee and chairman of the President's Committee on Employment of the Handicapped, notes, "the worst of times for those handicapped people still frozen out of society by outmoded attitudes."

It is easier to understand how disabled people can be frozen out of such important areas as jobs and education and housing when we see what barriers they still face in other, perhaps less important, areas. John Gibson, president of a group called WARPETH (World Association to Remove Prejudice Against The Handicapped) tells of having to use the freight elevator because he is in a wheelchair, of being turned away from a Miami Beach hotel even though he has a reservation, of having to use the garbage ramp to get into a restaurant, of paying two or three times normal auto insurance premiums (though disabled people do not have higher accident rates), of architectural barriers that keep him out of too many buildings, of having to bring along an adult companion or a doctor's certificate before he can travel by plane.

a look at institutions

One of the reasons society may now be ready to accept alternatives to the traditional ways in which disabled people live is that social historians, sociologists, and rehabilitation experts have begun to take a new look at institutions, their origins and their purposes, what they do *to* their residents as well as *for* them. Some of the insights are revealing.

■ *Institutions were not originally established for the sake of their residents.* The first asylums were created in the Middle Ages to house blind beggars, not so much to provide care for them—historians now agree—as to remove them from the sight of society.

Institutional segregation of the handicapped took hold in the United States between 1870 and 1880—supposedly because the blind (or the retarded, or the severely disabled) are happiest with their own kind. If this was ever true, most handicapped people no longer feel that way. On the contrary, many feel that if their "differentness" leads to their segregation, then their segregation *increases* their differentness.

An illustration: At an Easter Seal Society rap session for disabled adults aged 18 to 30, many of the participants referred to segregated schools as a disservice. One 22-year-old said bluntly that "by the time I was given the opportunity to mix with able-bodied peers, I considered myself to be some type of freak. . . . I've finally overcome this view of myself, but it took a long time. I don't think I would ever have felt this way if I'd grown up in the company of nonhandicapped children."

■ *Many institutions are built in isolated locations.* Ostensibly this was done for the good of the patient—though in fact for the comfort of society. We now know that such isolation may actually be harmful. Yet an agency that tries to locate even a small group of disabled people in a community usually meets resistance.

■ *Of all institutions, presumably hospitals are most clearly intended to be of benefit to their patients.* Yet one expert, W. M. Mendel, quoted in a publication of the New York State Department of Mental Hygiene, says "we observe in fact that hospitals are primarily a convenience for the physician who . . . finds it useful and efficient to collect patients in one place where they await his treatment."

The fact is that many institutionalized persons, particularly mentally retarded persons, are never treated at all; they are simply "warehoused." Perhaps the all-time record belongs to Martha Nelson, who died recently in an Ohio state mental hospital at the age of 103. She spent 99 years in the hospital, though at her death state officials admitted they were not sure why. In 1935 she was found to have an IQ of 27, but the jobs she did in the hospital, including laundry and housework, indicated higher intelligence.

How many others, especially the multi-handicapped, have suffered from such permanent placement? A British writer, James A. Loring, cites the case of a man admitted to a "subnormality hospital" at the age of 17 as a "spastic imbecile."

It was many years before it was discovered that he was of very good intelligence by an imaginative charge nurse who then taught him to read and write. His physical handicap [what is called here cerebral palsy] remains gross, but he has been able to write a short book which has been published, and he has developed an impressive knowledge of music. . . .

The point here is that . . . he was saved from a slow emotional and physical death more by luck than design.

■ *Institutions are not always the cheapest way for the taxpayer to provide care.* Take Mike and Earl, the quadriplegic bachelors in New York City. The total they receive from Supplementary Security Income and Medicaid is \$11,390 each per year. By comparison, 1974 figures for New York City show that a year in a health-related facility costs \$8,000-\$10,000 per person—somewhat cheaper. But Mike and Earl would need nursing home care, which averages \$15,000-\$19,000 annually; a chronic care facility would run even higher—about \$22,000 a year.

The fundamental question professionals are exploring is: is it a matter of certain “bad” institutions, or are even the best “bad”? Many experts feel the very concept of the institution, particularly the residential facility that provides only occasional medical care, is “bad.” It is said to depersonalize, to dehumanize; residents have almost no privacy, no personal possessions, and, perhaps most important, no say in decisions about themselves. The book *A Life Apart* goes further: it suggests that residential institutions are merely places of transfer from social to physical death.

parent problems

Do parents and families of disabled people share these views? Their feelings about institutions for their children are understandably complex. A few examples convey their concerns and their conflicts.

A common phenomenon in recent years has been the creation of a new, often small, residential facility, to meet the needs of a clearly established caseload of disabled adults, with parents usually spearheading the project. Then the facility opens for business, and suddenly the caseload “disappears.” For instance, Overbrook Hall, a Philadelphia residence for the multi-handicapped, had to close after seven years because it could never get more than 12 residents for its 20 beds. Yet the parents of the “caseload” had worked very hard for it.

Overbrook Hall is not an isolated instance. There is also Stoneywold, in New York, where a potential caseload of hundreds

was reduced to 25; New York City's Bird S. Coler Hospital, where a large projected caseload dropped to only five actual users; and Indianapolis, Indiana, where a possible caseload of 1,200 yielded only four applicants.

Parents naturally tend to reject institutionalization for their children and keep them at home as long as possible. To many parents, institutions or other residential facilities are for "after I die." Unfortunately, by their attitudes and by their treatment of their adult-but-handicapped "children," many parents make it a certainty that their children will never be able to live independently, that they will *have* to find shelter in some sort of risk-free environment when their parents die.

Mary Morrison, a personal management instructor, cites examples of such overprotection in an article in *New Outlook for the Blind*: Two 15-year-olds didn't know that you don't need the exact change to buy something in a store; they had never paid a clerk for anything in their lives. One college junior couldn't



butter bread; his mother had always done it for him. Another young man couldn't sign his name, only an X: "My father doesn't think I need to be able to sign things myself. He'll do it for me."

What about the schools this young man attended, Mary Morrison asks, which also never taught him to sign his name? "Could it be that the idea of these young people endorsing their own paychecks, for example, was never really taken seriously by anyone? That dependence was forever assumed?"

The net result is that disabled people often reach young adulthood in a state of what has been called "conditioned helplessness." By the time their parents die, or some other emergency develops, Senator Robert Dole has pointed out, they have acquired an institutional mentality. He describes "a recent meeting in a large city where severely handicapped adults, their parents, volunteers, lay leaders and state officials were discussing . . . living arrangements. . . . No one ever raised the possibility of a noninstitutional setting. . . . The idea of increased self-sufficiency and independence in a private residential setting was foreign to them all."

the principle of self-help

Is this conditioned helplessness permanent and irreversible? The experience of Sweden's Fokus Society, a pioneering venture in providing alternative housing for handicapped persons, may be instructive.

Fokus was set up in the late sixties to provide apartments (plus "on-demand" services) to severely disabled adults. A 1972 report indicates that 77 percent of the tenants in the 168 Fokus flats were dependent on wheelchairs, another 14 percent on crutches; that 52 percent needed help in dressing, 36 percent with personal hygiene, and 18 percent needed help turning in bed at night.

Only 30 percent had come to Fokus from their own or boarding homes; 33 percent had come from nursing homes and 37 percent from their parents' homes. This may suggest why 80 percent of the residents were pensioners, out of work, when they moved in. After three years as Fokus residents *80 percent were either working or going to school.*

The reason for this dramatic turnaround is the principle of self-

help. "Within the limits of his ability," says Fokus' president, Dr. Sven-Olof Brattgard, "the tenant in a Fokus flat has to take care of himself and assume complete responsibility for his own life. He is in no way dependent upon Fokus for major decisions. Help . . . is provided by Fokus when needed, but the onus remains that of the tenant. . . . Such a person should be enabled to influence his own life and to make his own decisions. That is what independence is all about."

A psychological turnaround seems to begin almost immediately. After Mike and Earl had been living in their apartment for only three months, a clinical psychologist reported that "the benefits of this kind of experience in psychological terms are immeasurable. Both men are thriving. Both are happier, more energetic, and more outgoing than I have ever known them to be. . . . The environmental change has gone a long way toward alleviating the chronic depression which is part and parcel of chronic illness."

The clue to the lack of independent living opportunities for the disabled, suggests Dr. James Q. Simmons of the National Multiple Sclerosis Society, may be that "our present system is an outgrowth of seeing the individual patient only as a medical problem and not as he is—a human being."

If the patient is viewed as a person, independent living comes into focus not primarily as a place, or even a kind of place, but as a process. And as a process it is—like the living situations of the nonhandicapped—impermanent and changing. It envisages ordinary joys and ordinary disappointments, normal failures and normal successes, and above all, run-of-the-mill risks.

This concept of independence for disabled persons deals with each person as he or she is, and can be. Some disabled people will have to be ruled out—for instance, those who are attached to life-support systems and older adults who have been institutionalized most of their lives. For others, the question of who may be "too handicapped" to live independently should be answered only in individual terms, with programs tailored to the patient's needs, personality, and degree of impairment.

Michael, a 25-year-old moderately retarded resident of an urban New York group home, works as a shipping clerk for a commercial firm, takes a bus or subway to work every morning, pays for

his own lunch, buys some of his own clothes, is taking an evening course in ceramics, has acceptable social behavior. Why, he wants to know, can't he move out of the home into his own apartment?

some alternatives, old and new

For most mentally retarded and severely or multi-handicapped people in this country, the state institution has been about the only alternative to home care. So much so, in fact, that until fairly recently "government" responsibility automatically conjured up a picture of a multi-bed facility with a population in the hundreds, sometimes in the thousands.

There is a growing feeling, however, that the large institution is at best an unsatisfactory way to provide shelter and care—not only because of size and some of the other objections to institutional care already noted, but because the facility is often isolated, even if in a "beautiful location."

To reduce this isolation, a number of states are experimenting with alternatives which keep care/treatment/living facilities in communities, or close to them—and which have the added virtue of being considerably smaller than the traditional institution. Connecticut has led the way in decentralizing its facilities into smaller regional centers, though these may still accommodate up to 200 persons. Other states—among them California, Rhode Island, and Nebraska—are focusing on various kinds of regional service models.

In Nebraska, the state program also calls for providing a number of small group homes or hostels to be served by each regional center. *Group homes* generally house from five to fifteen persons; in adopting this concept, the states are borrowing a model pioneered by many of the voluntary nonprofit agencies serving disabled people. But the group home still carries some connotation of permanent placement. Though the line of demarcation is not rigid, a *hostel* is a more temporary shelter; and the *halfway house* is clearly designed to ease the transition of the handicapped person from the institution to the community.

There are a number of other alternatives, dependent in large part on the degree and kind of active care the individual may require. These run from the *hospital*, the *nursing home*, and the

chronic care facility, to a room rented from a family that will provide *foster care*, to living in a *residence hotel* or a *boarding-house*. There are also *intermittent* or *respite care* units, which may play an extremely useful role in providing temporary shelter for a handicapped person, a sort of vacation home to which he or she can retreat for a few days if need be. And to round out the picture of the existing alternatives, some groups now provide *day care* facilities. Though the latter have generally been thought of in connection with children, such services are also being found useful and appropriate for elderly and for disabled people.

group living

In Connecticut, an older group home may have as many as 200 beds. But a relatively new one near Bridgeport, set up in 1975, houses only 12 retarded adults. The trend is indeed to smaller units, but this is not the only change taking place in the traditional group living arrangement. The group home is still the model most often preferred, established, and operated by parents/nonprofit agencies, but almost none of the newer facilities can be called "typical." The physical form and location may vary from a home for 15 trainable adults in a rural Texas county to an Illinois proposal for a cluster of five or six small group homes in an urban neighborhood, to a group home that is actually a second-floor wing of an old hotel in Philadelphia.

The search for "a different kind of place" sometimes comes from a group of parents suffering from a blessed form of ignor-



ance—they do not know what “can’t be done.” But very often it is the organized agencies—and their professional leadership—which refuse to be satisfied with merely a smaller, “better” institution.

One type of independent living, similar to the choice of many nonhandicapped teenagers and young adults in recent years, involves three or four or more unrelated people renting or leasing a large apartment or a house (where this does not run afoul of local zoning or housing laws). They are not a “family” but a group, yet this is far from the traditional model of the “group home.” It might be called a *communal* or *shared living unit*.

The traditional group home almost always accommodates people with like disabilities. In the shared unit, people select each other because they have like interests—some of the residents might not even be disabled. In the group home, the agency provides funding as well as supervision. In the shared unit, the tenants provide the funding and no one supervises. In the group home, the “professional” is a caseworker, a counselor—and is usually there first. In the shared unit, the only “professional” (if any) is a cook-housekeeper, hired by the tenants.

Even professionals who advocate such a living unit feel that it may not be practical for all disabled people. Certainly not everyone—disabled or able-bodied—can cope with group living. One knowledgeable professional suggests that for the disabled person the strongest asset of the shared unit is the possibility of mutual help; however, that would have to prove itself in practice over a period of time.



Professionals and the organizations that serve disabled people have begun to look at housing facilities as a key aspect of a whole constellation of services designed to help the handicapped person realize his full potential, to give him a chance—if he wants to take it—to live as others do.

If this is to be accomplished, says a United Cerebral Palsy Associations (UCPA) statement, “the program of any living arrangement . . . should provide opportunities for [the person] to learn increasingly complex skills, which will lead to more control over himself and his environment.”

“graduation” programs

Many voluntary agencies are combining existing “competence” training, training in daily living skills, with group home or apartment living. In some, the living arrangements are purposely time-limited, in others they are open-ended—to remove pressure from the people trying them—but with the emphasis on their transitional, independence-oriented character. Residents are not so much “housed” as they are educated, trained, prepared. There are even programs offering more than one kind of living arrangement to help residents graduate into the community, each arrangement representing an increased level of independent community living.

Larry, in his thirties, grew up in an institution for the retarded. Now he lives in the Elwyn Institute’s group home, in one of 35 apartments leased in Philadelphia’s old Sheraton Hotel. Called Chestnut Hall, it is considered a “halfway house” (Elwyn also has a “quarterway house” apartment program at a larger institution), a transitional step toward independent community living. Before the sixties, Elwyn Institute was a traditional custodial institution for mentally retarded patients with IQ’s ranging from 45 to 80.

Larry rides his ten-speed bike every day to his job in an electronics factory; he and his roommate take care of their apartment, cook their meals, use the coin-operated washing-machine and the hallway pay telephone. A married couple living in the same wing of the hotel provide advice and guidance (rather than supervision).

Larry may eventually “graduate” to a garden apartment in the Centerpost complex, where Sheila and Marie live. The process that began before he moved into Chestnut Hall is continuous: not only have Larry and others been helped to develop work skills, to cook and to shop, but staff and outside specialists provide workshops and classes and seminars on budgeting and banking, on personal grooming, job interviews, socializing, sex education, and learning to drive. There are planned recreation programs, and—most important—Chestnut Hall residents are given their own keys when they move in. It is a program, to quote its director, “allowing for the risks involved in the adventure and experimentation. . . .”

learning real-life skills

Programs like Elwyn’s are often formalized under the heading of “competence training” or “living skills” curricula. One such program for people with cerebral palsy, some of whom may also be retarded, was recently described in *START*, a publication of UCPA.

The program teaches: (1) personal skills such as dressing, self-feeding, bathing, transfer to and from a wheelchair; (2) environmental skills, such as telling time, using coins and bills, answering the telephone; (3) homemaking, including making beds, washing dishes, cooking, marketing and budgeting; (4) shopping for clothing; and (5) travel on public transportation.

In such programs, skills are not taught as abstractions but as part of a concrete, goal-oriented design. “The student will be able to perform all tasks necessary to function independently in a residential environment,” says the American Foundation for the Blind (AFB) in *Toward Independence*. “A classroom situation is to some extent a sheltered environment,” the manual notes. “Some programs may find it advantageous for the student to live in a ‘halfway house,’ for example an apartment, prior to leaving the program. The student is then placed in a realistic position of having to apply the skills taught in the classroom.” AFB suggests that as the blind student’s “leaving date” approaches, specific questions like the following should be asked:

“Has the student made plans to move into an apartment? If so, has he been oriented to the neighborhood, local supermarket, laun-

dromat, local stores, clinics, pharmacy, bank, post office, library, etc.? . . . Is the student moving into an unfurnished apartment? If so, does he know the cost of furniture and places to buy furniture? . . . Does he have a knowledge of telephone bills, gas and electrical costs? . . . Does he know how to get . . . to his place of work?"

To help blind people apply the skills, the Cleveland Society for the Blind first began to rent apartments around 1970, moving "trainees" into them under the supervision of a resident counselor. Among the advantages are a transfer of the techniques and skills taught at the center to the real-life setting of the apartment building and the opportunity to live together in a freer community and, more importantly, among sighted neighbors.

The Canadian Association for the Mentally Retarded suggests a three-stage progression toward independent living: (1) the apartment cluster, comprising several nearby apartments functioning more or less as a unit, and supervised by staff members living in one of them; (2) the co-residence apartment, with one or two staff members and several retarded people living together as roommates and friends; and (3) the maximum-independent apartment, occupied by two to four retarded adults.

The hostel apartments provided by UCP of New York City are also intended to be transitional, even though up to 40 percent of the cerebral-palsied tenants may wind up living in them permanently. According to UCP housing director Eleanor Younker, the residents were selected "because it was felt that they had the ability to adjust to apartment living, and that they have the potential for further development in self-care skills and personal management. . . . It is anticipated that some of these people . . . will be able to . . . move into their own apartments either in the same building or, even better, in other parts of the city."

The "same building" is Tanya Towers, built by the New York Society for the Deaf, where UCP has leased an entire floor of 13 apartments. (Half the cost of running the hostel, incidentally, is provided by the New York State Department of Mental Hygiene through contractual agreement; the other half is offset by the residents' Supplementary Security Income checks, with something left over for personal spending money.)

the question of special facilities

Tanya Towers is one recent example of housing built especially for the handicapped. An older development, Center Park Apartments, was built in 1969 by the Seattle Housing Authority as barrier-free housing for people with muscular dystrophy or other physical disability. They represent an area of controversy: should special—and separate—facilities be built and provided for people with special problems and needs? The argument about specialized housing revolves around the need for special architectural design, adaptations, conveniences, and protection versus the danger of self-segregation and isolation.

One group that chose such a separate facility was Creative Living, a Columbus, Ohio, nonprofit agency. Its single-level apartment complex—one of the first privately developed housing facilities for the disabled—was opened in October 1974 with a \$333,000 mortgage financed through the U.S. Department of Housing and Urban Development (HUD). There are 18 apartments surrounding an enclosed courtyard, a spacious common lounge, a reading room, an office for the attendants.

A group that changed its mind about from-the-ground-up housing for the disabled was the Eastern Paralyzed Veterans Association (EPVA). These paraplegic veterans, about 98 percent of whom spend most of their waking hours in a wheelchair, were faced with the normal choices of the severely disabled: to remain institutionalized, or to live with parents or relatives in a family household, usually one so inadequate physically that the paraplegic person becomes a virtual prisoner, totally dependent on others.

“For a long time,” reported Joseph Chasin, one of the veterans, “we felt that the only solution to the problem was a residential apartment building designed specifically for wheelchair living. It would offer many advantages: the privacy of individual apartments . . . adequate parking . . . communal facilities . . . an emergency alarm system with a fulltime attendant . . . low rent.”

Their “dream” began in the early sixties; their vain search for funding turned it—for a time—into a nightmare. In January 1966, the EPVA received New York City Housing Authority approval, hired an architect, applied for financing. But then, during

the Vietnam War, federal funds for housing were cut back drastically and no other financing could be found.

They now feel their "failure" was a blessing in disguise. During the years of searching, says Chasin, "our philosophy of housing for paraplegics changed. . . . We now felt that an apartment building solely for the wheelchair-bound would segregate these individuals from the community. So when early in 1972 an idea was presented . . . for a transitional housing program based on the concept of renting and modifying individual apartments in existing wheelchair-accessible buildings, we knew we had found the answer to the problem."

The EPVA leases all the apartments, equips them so the veteran will not have to face heavy expenses when he leaves the hospital, makes necessary minor modifications (with the approval of the landlord), and continues to provide necessary supporting services.

But, as in Sweden's Fokus flats, "residents . . . are responsible for rent . . . food, housekeeping, telephone and electricity costs, exactly the same responsibilities faced by any other individual in the community. Our . . . staff has helped, and will continue to help residents acquire suitable permanent housing to which they will move when they are ready for transition." They are also assured by the Veterans Administration that they can move back to a VA hospital at any time.

After the first year and a half, six paralyzed veterans had graduated to independence, others were preparing to do so. But "not every resident has successfully made the transition," Chasin reported. "Perhaps he was not yet ready. But the program gave him the opportunity to find out for himself."

"out into the world"

Why did the veterans want to risk it? Why the emphasis on apartment living?

What generally begins as a strong but negative goal—*not* to live in an institution, *not* to be a child in one's parents' home forever—often takes on a strongly positive aspect later: "For us, really getting out into the world, being a part of the mainstream—all the generalizations we'd talked about—meant in actual practice, when we discussed it, just living like everyone else lives. In

Brooklyn, that's in an apartment," says a newly married couple, both in wheelchairs.

While the problems of "community living" for the mentally ill are not covered in this pamphlet, it is worth recording that a recent report on Bronx (New York) State Hospital, noting that 80 percent of the patients no longer needed psychiatric care, declared that "more than half of the hospital patients could be discharged if adequate living facilities were available for them."

One apartment living program for former mental patients—Fountain House, in New York City—has been in operation since 1958. It has leased some 50 apartments in various sections of the city and made them available to returning patients, who can stay on as long as it is helpful. Some go on to rent their own apartments. On a smaller scale, four women—after many years in an institution—have for more than two years been sharing an apartment rented by the Rockland, New York, Hospital Guild.

Perhaps the largest transitional-housing apartment program for severely handicapped people is the Physically Disabled Students' Program at the University of California, in Berkeley, initiated around 1970. The program was created and run by disabled students and former students, with the assistance of able-bodied volunteers.

After three years, the program was not only assisting 78 quadriplegics to live independently in the community, plus ten more in a residence program, but had been responsible for the creation of the Center for Independent Living, which offered similar services to all disabled people in the community.

independent living

Certainly the program simplest in basic concept and least costly to the sponsoring group was that developed by some New York volunteers, and now known as Independent Living for the Handicapped. The sponsors would even deny that it was a formal program. "Whenever a couple of people in wheelchairs asked us to help them get an apartment, we did. And after they moved in, we just stood by if they needed us."

Mike and Earl are among the 37 people who "moved in." "There never was a plan or a schedule for setting up the individual living



units,” recalls Nicholas Pagano, the sole professional then involved. “The only reason that there are 22 such units now is that we started one whenever a couple of people decided *they* wanted to start one.”

The first (and almost the biggest) stumbling-block, he recalls, was apartment hunting. Most of the leads came at first from newspaper ads. Later there were also some sympathetic real-estate men. “Accessibility” was put to an automatic test: the apartment-hunters could tell immediately whether their wheel-chairs could navigate hallways and doorways; sometimes they didn’t get past the building entrance.

Like everyone else, the disabled people were usually forced to choose between the ideal and the available, between waiting for the perfect apartment or settling for something that needed adaptations. Pagano intervened in only one kind of decision: based

on his professional background, the experience of other groups, he insisted that non-related roommates each have a separate bedroom, their own private living-space.

If there was one single moment at which the disabled person did in fact have to decide whether he or she really wanted to take over the responsibility for his own life, it was the act of signing the lease. It was the tenants—not Independent Living—who always did so.

Lease-signing was in effect the moment of truth for severely disabled people who had always had their decisions made for them by parents or professionals. It was—all wrapped up in one—choosing a roommate; taking on responsibility for budgeting, for spending and buying, for living within a fixed income; procuring services, hiring or firing housekeepers and home health aides. For people from basically risk-free environments, it was a commitment to take on normal risks—plus some special ones.

“The day I decided to stick it out, I knew it was going to be hard,” says one young woman with cerebral palsy. The day her father walked out of the apartment they had shared she had an immediate decision to make: to go into an institution or to try independence. “But I was ready to go through anything to stay out of an institution. I *had* to try—even though I really didn’t know if I could accept life on my own.

“I didn’t know if I could learn what I had to do; I wondered if after a while I would want to pull out altogether. But now I’ve learned I *can* do it. I love it. I wouldn’t change for anything.”

help—and how to get it

What makes this kind of independent living possible are two new developments with regard to help and service—one inside the apartment, one outside. The “inside” help is legislation that allows funds to be channeled directly to the disabled person rather than through institutions or service agencies. And outside the apartment, these agencies have come to realize that they will not need to provide every necessary service, that their help may only be needed to support, back up, supplement community services.

Direct financing. With the reminder that amounts and procedures differ in each area, a useful illustration might be a breakdown

of the funds Mike and Earl, the quadriplegic couple, were receiving early in 1975.

They are a "couple," even though they are unrelated bachelors, because Supplementary Security Income (SSI) says they are—and pays them at the rate of \$308 a month. In addition they are jointly allowed \$15 a day for a housekeeper (who cleans and prepares meals), plus \$36 a day for home health aides, who look after their personal needs and hygiene, put them to bed, spend the night in the apartment (each man has a mike next to his bed to call the aide, since neither can turn over in bed without help). This totals \$51 a day from Medicaid for two. (A doctor's certificate and proof of financial need are required for this assistance.) They also get transportation to doctors and clinics and \$20 a month each in Social Security benefits. By comparison, the cost in the hospital where they formerly were is now \$103 per day per person—\$206 for two.

It should be noted, however, that Mike and Earl are able to manage on their SSI income largely because their fixed rent is only \$59 a month. Others in the Independent Living group pay as high as \$200, and do need supplementation from their families or other sources. Proposed legislation would permit Medicaid to pay rent as well, to help the disabled and the elderly to continue living independently.

There is another method, already available, by which disabled people may get rent subsidies. Under Section 8 of the new Community Development and Housing Act of 1974, a public housing authority is permitted to sign long-term leases for apartments, in private as well as in public housing, and then rerent them to low-income handicapped people. The tenants pay a maximum of 25 percent of their income, HUD pays the rest. One place this is being done is Portland, Oregon.

If the disabled person doesn't want to live alone in an apartment, or with a disabled roommate, direct funding can also finance persons living in group homes or in shared living units. **The home health aide.** Experience indicates that having a helper at hand is an essential for severely disabled people who want to live independently. Not always a paid helper: handicapped husbands and wives often act lovingly in a "mutual servant" relationship.

And some roommates perform key services for each other: a quadriplegic student is the eyes for a blind classmate; a woman with cerebral palsy cares for a respiratory polio quadriplegic. A newspaper story describes how a 39-year-old retarded man and an 80-year-old grandmother have adopted each other: he does the marketing and the heavy work; she does the housekeeping—and makes sure he wears his rubbers in bad weather.

But most professionals are inclined to feel that such services will have to be paid for and provided by a homemaker-home health aide.

How to find a home health aide? Sometimes the agencies serving the disabled have their own listings and are able to send an aide in. An article in *Performance*, published by the President's Committee on Employment of the Handicapped, suggests that where there is no organization to provide attendant referrals, good sources are college bulletin boards and placement offices, friends who use attendants, local and college newspapers, employment offices, the local public health department and hospital bulletin boards.

In most localities, a private or nonprofit agency may be able to supply an aide. The National Council for Homemaker-Home Health Aide Services, Inc. will supply information on services throughout the country. National agencies serving the disabled (see page 28) may also provide information to meet special needs.

Hiring the aide may pose another problem for the disabled person, new—and uncomfortable—in the role of employer. Yet from the very beginning Mike and Earl, and the others in the Independent Living group, did their own interviewing, hiring, and firing. Nicholas Pagano feels that it was a major milestone on their road to independence, an essential step in their growing up, when Mike and Earl were able to fire their first aide because of incompetence.

One agency executive feels it doesn't always work out quite that simply. While, he points out, most agencies do try to encourage the highest possible degree of independence, "no client 'hires and fires' the home health aide from a reputable agency." Maybe he or she doesn't want a particular individual who is sent by the agency, "but the agency is in on the transaction."

Services. What about the whole gamut of services the disabled per-

son needs from the community in order to live in the community? Services that are automatically provided to—or not needed by—residents of institutions? Services like medical care, counseling, transportation? Consumer advocacy, financial advice, help with budgeting? Arrangements for a theatre party, social occasions?

For severely disabled people to be able to live successfully in any community, they must know what services are available, where they are, how to get them. Even with those who do not normally need active medical care or attention, the accessibility of medical services usually ranks first. Mike and Earl, after four years' practice in coping, arrange their own schedule of visits to clinics for checkups and regular care and arrange with Medicaid for the necessary transportation to the clinics; they have found a doctor who will make house calls, and a hospital that will admit them automatically in an emergency; and they have worked out a system of backup aides so they will never need to be alone.

All this Mike and Earl have done themselves; yet in a pinch they knew they could call on the Independent Living group—usually when they were faced with a new situation. That group clearly understood that even the most independent of severely disabled people cannot simply be set adrift in a community. The helping agency is at the least the psychological lifeline; it should also be ready—even if only on a standby basis—to:

1) *Fulfill the role of advocate*, or ombudsman, helping the disabled person to get services and support from government and voluntary agencies. "In an advocacy role," Stanley Thomas, Assistant Secretary of Health, Education, and Welfare, told professionals, "you can help [disabled persons] to learn and understand their rights, to feel competent in moving about in what will surely seem a bewildering world outside their institutions."

An Easter Seal Society spokesman adds an additional dimension to the agency's advocacy role: it needs to be "a champion of the rights of the handicapped and disadvantaged of this world"; to adopt "a public posture on behalf of handicapped people and their opportunities for full participation in community life."

2) *Provide counsel*—if asked—on such specific problems as budgeting, dealing with the home health aide, with government offices, or with unsympathetic landlords. It must also give counsel-

ing in such broad (and often frightening) areas as social relationships and human sexuality.

3) *Offer some sort of social programming*, particularly on a non-segregated basis; but not expect that every client will go to every carefully arranged theatre party, concert, ballgame, or get-together. Consulting with the clients, the agency must expect to arrange the details and the logistics.

4) *Provide transportation on demand*—free or at a nominal cost. This is the item most mentioned by disabled people living independently; it is difficult to obtain, and usually priced out of their reach. Not for medical purposes or for authorized schooling (which is provided by government bodies), but for social occasions, shopping, or just visiting. Despite the relatively high cost, the sponsoring agency is almost bound to provide some sort of jitney service.

To the handicapped man or woman, it should be added, each practical service provided by the agency also delivers an intangible service—a demonstration that the “connection” is still there, that someone still cares.

Architectural modifications. Providing services is likely to require some financial expenditure by the sponsoring group. Surprisingly, adapting the apartment for the tenant may not cost anything, or at most very little.

A major argument for building housing for the disabled rather than attempting to rent apartments in existing housing is that the latter requires a whole series of very costly adaptations. However, experience indicates that—as long as there is adequate space for a wheelchair—this may not be true.

For instance, Mike and Earl, among the most severely handicapped, needed hydraulic lifts and other equipment, and special phones and other gadgets—but no adaptations to their apartment at all. And in Berkeley, quadriplegics moved successfully into relatively unmodified apartments.

That is not to say that no adaptations are ever needed. But especially in urban housing projects, such relatively minor adaptations as widening a doorway, taking out a decorative wall, raising or lowering fixtures, can be made without the necessity for legal action or additional payment by the tenant.

Disabled people can sometimes make do with relatively few adaptations. For instance, after multiple sclerosis had completely disabled John, the visiting nurse had to request only six modifications for his apartment: (1) adjustment of phone, door-latch, and thermostat for wheelchair reach; (2) built-up toilet seat; (3) straight chair in the bathtub and grab bars alongside; (4) lubrication of windows for easier opening; (5) lowering of clothes rack; and (6) replacement of gas stove by electric stove.

"We often found," reports the Independent Living group, "that it was easier for disabled people to adapt to apartments than to adapt the apartments to the people." Why would people with more than their share of problems be willing to take on additional ones? The clue may lie in a comment by British writer James A. Loring, though he was discussing institutional, rather than independent, living: "The width of doors and the gradient of ramps are very important, but they have only a marginal influence on people's lives. . . . Human relationships are critical matters and it is the quality of these relationships that counts."

"children no longer"

What is most important to the disabled person, Loring is suggesting, is how others feel about him, how he feels about himself and his life. Ernest Simmons is a polio victim, confined to a wheelchair, with limited use of his arms and legs. When he lived with his sister, he felt "trapped, always having to ask people to do for me all the time."

Objectively, perhaps, little has changed. He still has attendant service when he needs it: the likelihood is that someone will always have to "do for" him. But Simmons now has his own apartment: "It changes my whole outlook on life," he says. "It gives me a sense of freedom I never had."

John Kemp, a congenital quadruple amputee, speaks of the sense of accomplishment and independence he derived from an Easter Seal Society program. "There isn't anything more sacred" than independence, Kemp says; yet he has no illusions: "Although many handicapped people will never enjoy it totally, independence is the element they really want most."

In many respects, this is still "the worst of times" for the

handicapped. Yet it is evident that the barriers are indeed beginning to give way—if all too slowly—in jobs, in transportation, in architecture, in education. Some few have even surmounted what appears to be the last, the most difficult, barrier: the chance to live independently.

Diane Lattin, who lives in Washington, D.C., drives a car with hand-controls, gets her wheelchair into and out of her car by herself. She and her roommate, she writes, “though fairly severely disabled, live totally independent lives, working each day, traveling where and when we want. Ours is not the cleanest apartment in Washington, D.C., but that has nothing to do with our disabilities—we are just lazy. With a little ingenuity and common sense, I am sure our life is lived each day essentially no differently than yours.”

Certainly not all people who are physically or mentally disabled are like Diane Lattin and her roommate, able to live *totally* independent lives. But most can live *more independent* lives than they do now.

For the disabled teenager or young adult now living in an institution, or in his parents' home, the ultimate answer may not be an apartment of his own. Or a group home. Or a shared living unit. It may well be the institution he is in, or his parents' home for as long as they live.

But he wants to know: why isn't society providing alternatives? And opportunities? Why can't he too be free to choose like everyone else? Why must he be content to get only *what he needs*? Why not sometimes—again like everyone else—*what he wants*? The way Harold Russell puts it: “I see handicapped people demanding as full a life as all Americans are entitled to—and not being content with reasons why they can't have it.”

Demanding a chance to live independently. Knowing that there are risks as well as joys involved.

“Once upon a time,” Diane Lattin wrote, “people with disabilities were taken care of as children were. But as the years have passed, the world has changed. And disabled people have changed too. We are children no longer. With help, and sometimes without it, we have come to see ourselves as each man's equal.

“We are ready to succeed, or fail, on our own.”

for further information

- American Foundation for the Blind, 15 West 16th Street, New York, New York 10011.
- Muscular Dystrophy Association, Inc., 810 Seventh Avenue, New York, New York 10019.
- National Association for Retarded Citizens, 2709 Avenue E East, Arlington, Texas 76011.
- National Council for Homemaker-Home Health Aide Services, Inc., 67 Irving Place, New York, New York 10003.
- National Easter Seal Society for Crippled Children and Adults, Inc., 2023 West Ogden Avenue, Chicago, Illinois 60612.
- National Multiple Sclerosis Society, 205 East 42nd Street, New York, New York 10017.
- President's Committee on Employment of the Handicapped, Vanguard Building, Room 636, 1111 20th Street, N.W., Washington, D.C. 20210.
- President's Committee on Mental Retardation, GSA Building, Room 2611, Seventh and D Streets, S.W., Washington, D.C. 20201.
- Rehabilitation Services Administration, Division of Developmental Disabilities, 330 C Street, S.W., Washington, D.C. 20201.
- United Cerebral Palsy Associations, Inc., 66 East 34th Street, New York, New York 10016.

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